

**GENETIC DISORDERS AND PASTORAL CARE:
IMPLICATIONS FOR THE CHURCH**

**A Professional Project
Presented to
the Faculty of the
School of Theology at Claremont**

**In Partial Fulfillment
of the Requirements for the Degree
Doctor of Ministry**

**by
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This professional project, completed by

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*has been presented to and accepted by the Faculty
of the School of Theology at Claremont in partial
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DOCTOR OF MINISTRY

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ABSTRACT

Genetic Disorders and Pastoral Care: Implications for the Church

by

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The church and its professional clergy often have little awareness of genetically caused health issues and have little or no training in how to assist families in such circumstances. This project deals with the problem of often inadequate pastoral care to families who are in constant and on-going crisis due to having one or more severely handicapped and/or terminally ill children with genetically caused diseases who are cared for at home.

In every congregation there are genetic issues and problems. In some instances, families have one or more severely handicapped and often terminally ill children. This project focuses on families and persons affected with a group of diseases known as leukodystrophy, as an example of situations which often precipitate the crisis concerns being described. This project explores some possible ways of doing more adequate pastoral care in these tragic circumstances.

Chapter 1 presents the basic outline of the project. Work previously done in the field is reviewed and the scope of limitations of the project are identified.

Chapter 2 reviews the biblical literature and other studies which have been done previously in the area of pastoral care with handicapped and disabled persons. The theodicy of suffering and evil is addressed from the viewpoints of liberation ethics and process thought.

Chapter 3 gives a detailed explanation of the leukodystrophies as the specific group at which the project is addressed. Pastoral care needs are explained in the light of this tragic group of diseases.

Chapter 4 explains a research questionnaire which was used with leukodystrophy families to help identify specific pastoral care needs. Areas of concern and targeted needs of pastoral care are lifted up and identified.

Chapter 5 offers some models of response for pastoral care including seminary curriculum, local church programs, and one to one activity on the part of the pastoral care giver. This concluding chapter offers some practical suggestions for increasing awareness and care.

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The families, friends, and scientists in the United Leukodystrophy Foundation have helped make this research possible. Ron and Paula Brazeal, and Hugo and Ann Moser have been sources of continuing inspiration.

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**To
Kristy**

**"Let the children come to me, and do not hinder them;
for to such belongs the kingdom of heaven."
Matthew 19:14**

CHAPTER 1

Introduction

Problem Addressed by the Project

The church and its professional clergy often have little awareness of genetically caused health issues and have little or no training in how to assist families in such circumstances. This project deals with the problem of often inadequate pastoral care to families who are in constant and on-going crisis due to having one or more severely handicapped and/or terminally ill children with genetically caused diseases who are cared for at home.

Importance of the Problem

We live in a time in which 15 percent of the population is disabled. Twelve million Americans, for example, have some type of genetic condition in their family. Each year, 210,000 babies are born with genetic disorders or birth defects. One third to half of all childhood admissions to hospitals are caused by genetic disorders.¹

In every congregation there are genetic issues and problems. In some instances, families have one or more severely handicapped and often terminally ill children. This situation places tremendous strains on the marriage relationship and the family constellation as a whole. Many handicapped children suffer from progressive and degenerative neurological disorders which are eventually terminal. The course of

¹ Frank Seydel and David Parker, "The Clergy and the Genetics Patient," paper developed for the Program for Pastoral Care Education in Genetics, Georgetown University Medical Center, Washington, D.C., photocopy, 1988, 1.

the disease can be severely painful for the patient and difficult to cope with for the care-givers in the family.

Quite often, such children are cared for at home and not in hospital medical centers. They often die quietly and out of public view. However, their circumstances may be very desperate.

Thesis

The religious community and its professional clergy often have little awareness of genetically based handicapping conditions and have little or no training in how to assist families in such circumstances. This project is designed to assist the religious community in becoming aware of families with handicapped and terminally ill children and to learn how to render appropriate and meaningful pastoral care in such circumstances.

Definitions of Major Terms

Genetics

Genetics is the branch of biology that deals with heredity in variation and similar or related animals and plants. The subject matter of human genetics is the analysis of human variation. Human genetics has long been entangled with issues of privacy and confidentiality, autonomy and control. Genetic testing has the capacity to generate huge quantities of genetic information. There are all sorts of arguable issues about genetic information. The confidentiality of genetic information is certainly an issue. There are times, however, when genetic information should perhaps be shared with family members whose own reproductive choices could suffer if they remained in

ignorance. Ethical and legal aspects of advances in genetic testing will have profound affects upon human life as the mapping of the entire human genome proceeds.

Ministry

Ministry is the task of doing grass roots theology in the community. This is the business of interpreting the word of God within the events of human life. Within the Christian tradition, this means spelling out the gospel according to Jesus Christ both locally and globally. This means the sharing of the gracious granting of wholeness to all people. As Harold Wilke has said:

The doctrine of "the imputation of wholeness" the height of the gospel, is that God loves us unreservedly, and in Christ has given the divine being for our own sins and shortcomings. The salvation we cannot earn for ourselves, the wholeness we cannot achieve individually, God offers to us in the gracious gift of Christ on the cross of Calvary.²

Ministry is also the openness to the integration of persons with disabilities, including genetic issues, into the life of the church. The ministry of the church of Jesus Christ is a ministry of caring for all people, regardless of their condition or station in life.

Handicapped

Handicapped identifies those persons who include the disabled and chronically ill, the crippled and the invalids; those who suffer because of mental and physical impairment. Persons who suffer because of genetic disability are also included as those who are handicapped.

² Harold Wilke, Creating the Caring Congregation: Guidelines for Ministering With the Handicapped (Nashville: Abingdon Press, 1980), 21.

Leukodystrophy

Leukodystrophy refers to a group of disorders which affect the brain, spinal cord, and peripheral nerves. These are disorders that are genetically determined, and in the absence of therapy, slowly get worse. Leukodystrophy affects the myelin sheath of the brain mainly and out of proportion to other parts of the nervous system.

Terminally Ill

To be terminally ill is to be affected by a physical disorder in such a way that the end result is the death of the patient. This is caused by the disease or disorder when it does not respond to therapy or medical treatment.

Pastoral Care

Pastoral care is the ministry of presence of the pastor, spiritual leader, or lay volunteer representing the body of believers. It is also the ministry of the faith community as a whole. It may include the practice of pastoral psychotherapy. It is pastoral advocacy and constructive response to the needs of the human agenda. It refers to the shepherding, counseling and guidance duties of a pastor. Pastoral care has also come to be known as a specialized field of the practice of ministry. Pastoral counseling, for example, is a recognized discipline in psychotherapy. Pastoral care embodies the one to one relationship of the pastor and the parishioner, usually in a special caring and uplifting manner. It is also the caring extended by the church congregation.

Church

The church is the religious community. It is the body of believers who comprise a constituency or a congregation of a defined faith or denomination. In Christianity, for example, this may be a local church congregation.

Work Previously Done in the Field

For some years there have been a nodding acknowledgement among pastoral counseling practitioners that people who are disabled or handicapped have special needs. For example, Wayne Oates in his Pastor's Handbook notes the often inadequate responses to the chronically ill and handicapped and urges the hesitant care-giver to probe further the specific pastoral care needs.³ Oates offers little, however, to change the typically anemic pastoral care response.

Howard Stone suggests in his book, Crisis Counseling, that lay persons in the local congregation can be trained as care-givers to augment what the pastor does not have time to do or is not trained to do to assist in crisis care-giving.⁴ Stone is at least acknowledging a possible avenue of support and assistance, particularly in those situations which are obviously categorized as being of a crisis nature.

A significant attempt to address the area of disability and pastoral care is Pastoral Care with Handicapped Persons by Lowell G. Colston. Colston is a handicapped person himself and has been able to pull together a number of helpful and practical approaches to ministering to persons with handicapping conditions. He describes a kind of ministry of presence that he calls "pastoral advocacy" which is a type of mutual caring ministry.⁵ He stresses the importance of simply being "with"

³ Wayne Oates, Pastor's Handbook, 2 vols. (Philadelphia: Westminster Press, 1980), 1:64-65, and 2:105-07.

⁴ Howard Stone, Crisis Counseling (Philadelphia: Fortress Press, 1976), 68-74.

⁵ Lowell Colston, Pastoral Care With Handicapped Persons (1978; reprint, Ann Arbor: UMI, Books on Demand, 1991), 6-7.

the person in pain and to "manifest care and concern."⁶ Colston also offers concrete suggestions for supporting parents of handicapped children and the development of a caring congregation.⁷

The most visible and notable work on the subject to date is that of Harold H. Wilke, Creating the Caring Congregation. Wilke is a handicapped person, a minister in the United Church of Christ, a faculty instructor at Union Seminary in New York, and founder of the Healing Community. Wilke is determined to assist the local congregation in what he calls, "recapturing our charter in the religious community."⁸ He sets forth a series of guidelines which began as an action-research program in 1974 and were published in this book in 1980 (now in its fourth printing). Wilke believes there is a potential of helping nearly 100 million members of churches, parishes, and synagogues to respond to the needs of handicapped individuals.⁹ Wilke is a major advocate of overcoming that within the Biblical tradition itself, not just interpretation, where there is a tremendous negative response to physical disability.¹⁰ Wilke points out that handicapped people are too often left out of our churches. "They are the invisible people of our society, kept out of sight and out of mind."¹¹

⁶ Colston, 6-7.

⁷ Colston, 6-7.

⁸ Wilke, Creating the Caring Congregation, 11.

⁹ Wilke, Creating the Caring Congregation, 12.

¹⁰ Wilke, Creating the Caring Congregation, 22.

¹¹ Wilke, Creating the Caring Congregation, 52.

Wilke goes on to develop a framework for use by local congregations for creating a caring community.

The problem still remains, however, of how to minister to the particular situation of families who are in constant and ongoing crisis due to having one or more severely handicapped and/or terminally ill children who are cared for at home. This project intends to focus on this particular situation by contributing to the awareness of an existing need and by making some suggestions for meaningful pastoral care practices in such circumstances.

Scope and Limitations of the Project

This project focuses on families and persons affected with a group of diseases known as leukodystrophy, as an example of situations which often precipitate the crisis concerns being addressed herein. I am the father of a child affected with metachromatic leukodystrophy, a terminal degenerative neurological disease. With my wife, Colleen, I share the office of Vice President of the United Leukodystrophy Foundation, an international medical society serving families and researchers in over thirty-one countries.

While there are other diseases and circumstances with children and families which carry the same or similar pastoral care concerns as those affected with leukodystrophy, this project will exclude those categories in order to focus on leukodystrophies as precise examples of my thesis. Regardless, it remains my contention that the religious community and its professional clergy often have little awareness of these kinds of situations and have little or no training in how to assist

families in such circumstances. This project will explore some possible ways of doing more adequate pastoral care in these tragic circumstances.

Procedure for Integration

As cited above, both Harold Wilke and Lowell Colston have addressed the pastoral care needs in general, of handicapped and disabled persons. Both theologically and practically, they have offered basic guidelines for clergy and congregations to enable more effective involvement. Their respective points of view will be briefly explored. Alongside of Wilke and Colston, this project will examine current bio-ethical literature and other writings. For example, John Cobb believes that the acknowledgement or recognition of God's incarnate presence moves to the heart of the counseling situation.¹² There needs to be the recognition that pastoral care and counseling bridges several traditional disciplines when it is effective. In his essay, "Authority and the Profession of Medicine," Stanley Hauerwas maintains, "medicine requires the existence of another institution to be able to keep its extremely significant, but limited, task limited."¹³ Pastoral care needs to readdress its role in the healing community.

In addition to library research, the writer brings to this project a body of empirical knowledge gained after more than ten years of advocacy and medical

¹² John Cobb, Jr., Theology and Pastoral Care (Philadelphia: Fortress Press, 1977), 52-53.

¹³ Stanley Hauerwas, "Authority and the Profession of Medicine," in On Moral Medicine, eds. Stephen E. Lammers and Allen Verhey (Grand Rapids: Eerdmans Publishing, 1987), 525.

research in the field of leukodystrophy. A pastoral care research questionnaire used with a selected number of leukodystrophy families is also evaluated in light of the thesis of this project.

Chapter Outline

Chapter 1 is the introduction. This is the basic outline of the project. Included are the definitions of major terms, an overview of work previously done in the field, and a statement of the scope and limitations of the project. The procedure for integration of theological and functional disciplines is described.

Chapter 2 reviews work previously done in the field. This is an overview of current literature which is somewhat limited due to the subject and scope of the project. Included in the review are Harold Wilke, Lowell Colston, Wayne Oates, Howard Stone, John B. Cobb, Jr., Andrew D. Lester, Frank T. Hainer, Karen Waggener and Robert Standhardt, and Robert Pietsch. A discussion of the pastoral care problem of theodicy from the viewpoint of Rebecca Chopp (liberation ethics) and David Griffin (process thought) is included in this section. Works by Harold Kushner, Gordon Jackson and Albert Harper are also reviewed.

Chapter 3 identifies the pastoral care needs within the scope and limitations of the project. The leukodystrophies are the specific group at which the focus of the project is addressed. Genetics as issues with families and children and the special circumstances of persons who are handicapped and terminally ill are discussed.

Chapter 4 is a review of the research questionnaire and responses by leukodystrophy families. The questionnaire was designed specifically for this project study. Areas of concern, responses to pastoral care, and targeted needs are discussed.

Chapter 5 addresses some models of response including the summary and conclusions of the project. Practical suggestions are offered for increasing awareness and care. Suggestions are made pertaining to proposed seminary curriculum, local church programs, and informed pastoral care. Practical applications of the theological categories described in the pastoral care problem of theodicy are also noted.

CHAPTER 2

Review of Work Previously Done

Recent Overview

As has already been indicated, when one looks at the very limited literature already done in the field of pastoral care and disability, Harold Wilke rapidly comes to the fore as being the most helpful and pragmatic in his approach to pastoral care to persons with a wide array of disabilities. The idea of genetic issues in pastoral care is a relatively new concept. It is now emerging as a frontier for pastoral care efforts and for general awareness of the church. This is due, in large part, to the mapping of the entire human genome, which is addressed in chapter three.

We live in a time when the needs and awareness of disabled persons have been lifted to the conscious awareness of society as a whole. The United Nations has undertaken a Decade of Disabled Persons campaign. The United States government has enacted legislation which deals with accessibility for disabled persons. In 1973 Congress passed Section 504 of the Rehabilitation Act, a law that prohibits discrimination on the basis of physical or mental handicap. In 1990, President Bush signed the Americans With Disabilities Act.

In the public as well as the religious arena, people like Harold Wilke are working to affirm the proper role of the disabled to all of society. Wilke directs an organization called the Healing Community, whose purpose is to advocate for access of all churches, temples, and synagogues to disabled persons.

Among the most recent advocates on the scene where genetic issues and disability are concerned are Frank Seydel and David Parker, originators of the program for pastoral care education and genetics at Georgetown University Medical School in Washington, D.C. It is important for clergy to understand what the field of genetics is all about, what genetic centers and genetic counselors do, and ways that clergy can be of assistance with persons and families who experience genetic loss or genetic concerns.

Theological Perspective

A question that must be addressed is how God is related to genetic disorders. As discussed further in Chapter 3, the Biblical literature is clear that pastoral care needs have always been with us where the handicapped and disabled are concerned. Doubtless, much of what the biblical literature portrays include persons who are disabled by genetic problems. Like the poor and the outcast, they have always been with us.

In terms of a handle for getting at the theological implications of genetic illness, I have found Rebecca Chopp's understanding of liberation theology to be helpful.

The two sources of theology are human existence and Christian tradition: From these sources theology draws material, criticizes positions, and anticipates new ways of being and doing in the world. Though the sources of theology remain the same, theological paradigms differ in how sources are understood, how issues are ordered, and what categories are used for interpretation. But in all theological paradigms, there is the attempt to become

a faithful interpretation of Christian tradition as well as a credible representation of human existence. Theology must be, at least in principle, accessible to human understanding and appropriate tradition of which it seeks to be a representation."¹

Chopp goes on to point out that, "in liberation theology, this entails the explicit purpose of seeking both to interpret both the language of God by the victims of history to be one voice of history's victims."²

Perhaps, then, the task of discussing genetic issues in theological terms is one which at first recognizes that God is present in all of creation, including persons affected with genetic disabilities. From that, Robert N. Pietsch has pointed out that "almost every major denomination has made a statement or statements concerning their churches' commitment to the immigration of persons with disabilities into the light of the church."³

Since 1977, almost all mainline churches have made some kind of national statement(s) concerning persons with disabilities and the involvement of those persons with the life of the respective denomination. Robert Pietsch has noted that, "They are historic statements in that they reflect an understanding by the church of a need never before articulated."⁴ Obviously, one of the greatest needs of the church is for

¹ Rebecca Chopp, The Praxis of Suffering: An Interpretation of Liberation and Political Theologies (Maryknoll, N.Y.: Orbis Books, 1986) 135.

² Chopp, Praxis of Suffering, 136.

³ Robert Pietsch, "What Ten Denominations Have Said About Their Commitment to the Integration of Persons With Disabilities into the Life of the Church, and How They Are Being Implemented in Orange County, California," photocopy, 1988, 1.

⁴ Pietsch, "What Ten Denominations Have Said," 12.

consciousness raising where issues such as disability and genetics are concerned. Strategies of ministry need to be developed. Both practical and theological education needs to take place if barriers such as ignorance and indifference are to give way to creative change in the lives of church congregations. Pietsch concludes his study by saying:

Perhaps there has never been a more opportune time for the church to become involved in such ministry. Though there are still many obstacles, there is a fresh awareness, an openness to the integration of persons with disabilities into the life of the church. Let us pray that the church not lose this opportunity for the sake of the completion of the community of faith, the good of the whole human family, and the glory of God.⁵

If we believe in the priesthood of all believers, then we must affirm that all persons, including those with genetic illness, are called into the life of fellowship in the church.

Persons with genetic illnesses and issues are among those who sometimes have severe physical and mental limitations. At the same time, however, they are truly human and they have the capacity for a relationship with God. They also have something to give as well as to receive in the life of the church and in the community. Many persons who suffer genetic disabilities and their families are not involved in the church. According to Robert Pietsch, "In Orange County, there are 58,266 persons with developmental disabilities, and yet only five percent of the churches have any ministry with them. Only one Presbyterian church in the Los Ranchos Presbyterian

⁵ Pietsch, "What Ten Denominations Have Said," 13.

(61 churches primarily in Orange County, California) has any extensive intentional ministry."⁶

Church and Biblical Attitudes

Harold H. Wilke points out in his article, " 'Mainstreaming' the Alienated," that

we have a history of keeping people out of sight, out of mind, a view that has been thought the proper thing for the church to institutionalize such persons; in many cases the church has turned over to secular society the keeping of such institutions. Several of our denominations have been leaders in this work, which is motivated by humanitarian concern and often is necessary, although institutionalization is not always the best solution. The church in Germany helped to create, both there and through churches in this country that follow their examples, the idea that institutions can best take care of alienated people."⁷

Wilke goes on to say,

But now, within our churches and in secular society, the process of deinstitutionalization is gathering force. For just one example, the number of persons in mental hospitals -- over a quarter of a million seven years ago -- has been cut in half over the past six years. Most of our state governments and the U.S. Department of Health, Education and Welfare follow an intentional program of deinstitutionalization. In many cases our churches have led the way."⁸

Certainly basic genetic education and sensitization would be a most useful component in pastoral care training. A few graduate theological schools are just now beginning to wake up and offer some courses which may include these issues in basic graduate theological education.

⁶ Robert Pietsch, abstract of "A Theologically Oriented Strategy of Ministry To/With Persons with Mental Retardation and Its Implications for the Church" (D.Min. diss., San Francisco Theological Seminary, 1986), 2.

⁷ Harold Wilke, "'Mainstreaming' the Alienated: The Church Responds to a 'New' Minority," Christian Century, 23 March 1977, 6.

⁸ Wilke, "'Mainstreaming' the Alienated," 6.

As indicated in Chapter 1, the literature concerning pastoral care and disability issues is somewhat sparse. There is even less where pastoral care and genetic issues are concerned. I have found the work of Karen Waggener and Robert Standhardt helpful where general biblical attitudes toward disabled people are concerned. They have reviewed the progression of ideas in both the Old and New Testaments. In the Old Testament, Waggener and Standhardt have divided the biblical references into four general categories or groups: community standards; metamorphic/prophetic usages; eschatological references; and individual stories.⁹

While genetic issues in particular are not identified in the biblical text, it is interesting to be aware of the variance in attitudes which do exist toward those whom the Bible views as disabled.

As Waggener and Standhardt point out:

the books of Leviticus and Deuteronomy contain several references to place and treatment of persons with disabling conditions within the Israelite community. Deaf, blind, or lame people were not to be objects of ridicule or abuse according to these texts: You shall not curse the deaf nor put a stumbling block before the blind. (Lev. 19: 14) A curse on him who leads a blind man astray on the road. (Deut. 27:18).¹⁰

It is clear that as far as community standards are concerned, disabled persons were not to be treated as outcasts; they were the responsibility of the larger community. The Hebrew community defined righteousness in part, as the sharing of responsibility

⁹ Karen Waggener and Robert Standhardt, "Biblical Attitudes Toward Disabled People," National Apostolate for Mentally Retarded Persons 17, no. 4, (Winter 1987): 2-5.

¹⁰ Waggener and Standhardt, 2.

for its members. 'I was eyes to the blind and feet to the lame' (Job 19: 15).¹¹

Paradoxically, however, the Hebrew community was not necessarily one of shared equality.

None of your descendants throughout the generations who have a blemish may approach to offer the bread of his God -- for no one who has a blemish shall draw near. A man blind or lame, or one who has a mutilated face or a limb too long -- he may eat the bread of his God, both of the most holy and of the holy things, but he shall not come near the vail or approach the altar" (Lev. 21: 17-23).¹²

In the Old Testament, persons with disabilities were not outcasts, but neither were they allowed equality and the opportunities of the other members of the community.

The Israelites appear to view persons with disabling conditions as less than perfect or whole. As noted above, the indication is that they were not allowed to perform the priestly functions. Eli the priest in I Samuel 4, is depicted as being nearly blind with old age, and overweight, but he is still functioning in his priestly role.¹³

There is clearly a mixed tradition. Waggener and Standhardt also point out that "the view of retributive justice (often called the Deuteronomic view) did develop to the point where handicaps as a punishment was the supported belief. This is evident in the arguments presented by Job's friends who claimed that he suffers because of his past sins. However, this is not the prevailing view in the legal scriptures."¹⁴

In their review of the Old Testament literature, Waggener and Standhardt have

¹¹ Waggener and Standhardt, 2.

¹² Waggener and Standhardt, 2.

¹³ Waggener and Standhardt, 2.

¹⁴ Waggener and Standhardt, 3.

clearly identified a mixture of traditions where attitudes toward disabled people are concerned. It is fair to say that the Old Testament views persons who were less than physically whole as somehow second class or in a lesser position of worthiness than those who are of sound mind and body.

The New Testament indicates similar attitudes and ideas to the Old Testament understanding.¹⁵ The New Testament tradition is, in large part, a carry over from the Old Testament understanding. Waggener and Standhardt are correct in pointing out that

however, one attitude which began in the Old Testament is becoming prominent in the New Testament. It is more important to be spiritually healthy than physically whole. Perhaps owing to the influence of dualists such as Plato and Aristotle, the Greek writers, appear to be telling us that 'flesh' is secondary.¹⁶

The difference between the Old and New Testament understandings is that in the New Testament God is the healer through Jesus Christ. The healing of attitudes is at least as important as physical healing in the New Testament understanding.

The apostle Paul is a prime example of the prototype disabled person and the relationship of the disabled to the Creator.

Paul becomes the predecessor for ministry by persons with disabling conditions, not just ministry for these persons. He has searched the worthiness and capabilities of all persons by his reference to being accepted as an angel of God in spite of physical imperfection. He helps us realize that all

¹⁵ Waggener and Standhardt, 3.

¹⁶ Waggener and Standhardt, 4.

persons have weaknesses. These may be for the glory of God, for it is in the manifestation of God's strength, that we realize our weaknesses and the need for the Divine Healer in all areas of our lives.¹⁷

The biblical literature is clear that pastoral care needs have always been with us where the handicapped and disabled are concerned. Even though the Bible does not identify diseases in the categories with which we have described, I have no doubt that much of what the biblical literature portrays include those persons who are disabled by genetic problems. It remains incumbent upon us to continue to minister to those who by the world's standards are not physically or spiritually whole.

Theodicy: The Problem of Suffering and Evil

In any theological discussion of pastoral care, one must deal with the question of explaining God's actions. One of the problems in pastoral care is the problem of theodicy. Rabbi Harold Kushner raised this issue so well in his book titled, When Bad Things Happen to Good People.¹⁸ Kushner's concern is the issue of theodicy, that is, the notion which we have inherited from the Hebrew tradition which suggests that evil is punishment from God. Related to this is the idea that evil comes in our experience in order to teach us. Suffering, therefore comes in human experience in order that we might learn; suffering teaches us. In this framework of thinking, God is all-powerful and creates or intends evil as well as good in the world. Evil, however, comes from the shadow side of God. The idea of shadow is a Jungian concept out of which evil arises from the corrective unconscious.

¹⁷ Waggener and Standhardt, 4.

¹⁸ Harold S. Kushner, When Bad Things Happen to Good People (New York: Schocken Books, 1981), 2.

As the father of a child who was stricken at the age of six with a rare genetic disease, I can clearly identify with Rabbi Kushner and the experience with his son, Aaron. My daughter, Kristina, is now 17 years old and has been under round-the-clock nursing care at home for nearly eleven years. She suffers from metachromatic leukodystrophy, a progressive and terminal neurological disease.

I can certainly identify with Rabbi Kushner's feelings wherein he says,

How does one handle news like that? I was a young, inexperienced rabbi, not as familiar with the process of grief as I would later come to be, and what I mostly felt that day was a deep, aching sense of unfairness. It didn't make sense. I had been a good person. I had tried to do what was right in the sight of God. More than that, I was living a more religiously committed life than most people I knew, people who had large, healthy families. I believed that I was following God's ways in doing His work. How could this be happening to my family? If God existed, if He was minimally there, let alone loving and forgiving, how could He do this to me?¹⁹

It is important to address the question of God's goodness and fairness in the light of things that happen to persons we know and care about. Where does one turn for strength and hope when tragedy such as genetic illness comes to a family? As Rabbi Kushner has said, "There is only one question which really matters: why do bad things happen to good people?"²⁰ Rabbi Kushner goes on to say,

The misfortunes of good people is not only a problem to the people who suffer and to their families. They are a problem to everyone who wants to believe in a just and fair and livable world. They inevitably raise questions about the goodness, the kindness, even the existence of God.²¹

Albert W. J. Harper defines theodicy as, "theodicy simply amounts to our

¹⁹ Kushner, 2.

²⁰ Kushner, 6.

²¹ Kushner, 6-7.

accounting, to the best of our human abilities, for the various degrees of good and evil from a divine perspective such that total responsibility stops not with humankind, but is carried as far as God himself and our attempts to reconcile the afflictions which all too often befall a suffering humanity."²²

In his essay, Harper maintains:

In the first place, theodicy, in itself as a science, cannot pretend to be adequate to explain, much less to fully control, all the many aspects of suffering. Secondly, suffering can never totally be abolished so long as we as human beings are to make moral progress in this life, or enjoy life in its fullness or enjoy life at all. It is contended that the pain of growth rather than the suffering of death should be the mark of moral advancement. Thirdly, there is no such things as an absolute suffering to which we are condemned in existence; the agonies of extreme suffering engendered largely by the fear of suffering may be greatly modified. Fourthly, we do not benefit because we conform to any or all forms of suffering, where as part of life and living, we conform to a certain degree of controlled suffering to which we become conditioned because we believe it will be thus to our benefit.²³

I have discovered that to get either a practical or a theological handle on suffering and the problem of evil is not easy. Obviously, evil is present in our world and suffering occurs. Innocent people, both parents and children, experience evil. It is, therefore, important for this study to address the problem theoretically and practically. There are, I believe, no pat answers.

For the purpose of discussion in this project, which is limited to pastoral care and those who suffer with genetic illness, I shall address two frameworks which are helpful in getting at the question of theodicy. First, a look at clergy ethics in the light of liberation theology will be discussed. Secondly, a process theodicy view will be

²² Albert W. J. Harper, The Theodicy of Suffering (San Francisco: Mellen Research University Press, 1990), iv.

²³ Harper, iv-v.

explored. Insights from these two theological perspectives will be appropriated in Chapter 5.

During the long years of my daughter's illness, as I and my family have suffered with her through this tragedy, I have searched for some meaningful frameworks of understanding. Where does one find caring and assurance for such a predicament as being victimized by a rare orphan disease?

Liberation Theology.

As Rebecca Chopp has pointed out,

Against the bourgeois subject, liberation theology listens to a new subject who suffers: these are the subjects of the underside, upon the margins, in death itself. These subjects are not written about in biographies or school books; these subjects are not filmed in soap operas or movies or mass culture; these subjects are not studied in ruminations of a narcissistic society. Though they have no objective records, these subjects have faces, stories, and testimonies. These faces, as the Latin American bishops at Puebla announced, are the subjects for a liberation theology:

- the faces of young children, struck down by poverty before they are born...;
- the faces of the indigenous peoples, and frequently of the Afro-Americans as well, living marginalized lives and inhuman situations...;
- the faces of the peasants; as a social group, they live in exile almost everywhere on our continent...;
- the faces of marginalized and overcrowded urban dwellers, who's lack of material goods is matched by the ostentatious display of wealth by other segments of society;
- the faces of old people, who are growing more numerous every day, and who are frequently marginalized in a progress-oriented society that totally disregards people not engaged in production.²⁴

While the above categories come out of current Latin-American society, it is easy for anyone who suffers and is disenfranchised to identify with the concern to make

²⁴ Chopp, Praxis of Suffering, 121-22.

changes in human existence. As Chopp says, "liberation theology" demands justice, equality, and freedom in Christian witness. Consequently, liberation theology is a new language of God, seeking in the present historical situation to be the voice of those who suffer."²⁵

For Rebecca Chopp, praxis is a major component of the discussion of liberation theology. She defines praxis as, "positively stated, the realization that humans make history and, negatively stated, the realization that humans cannot rely on any ahistorical, universal truths to guide life."²⁶ In Chopp's view, "Christianity is understood as a particular religious praxis, and religion is understood as a part of human praxis."²⁷ For the liberation theologian, then, praxis brings together action and reflection along with transformation and understanding. Praxis becomes the forum where Christians, "struggle to 'live out' their faith through prayer, meditation, and religious discipline or through action, witness and prophetic testimony, or through both."²⁸ Liberation theology is unique. "Liberation theology asks a quite different question from that of modern theology, the question of massive public suffering."²⁹ In liberation theology, suffering confronts and disrupts human existence with the lifting up of the agonies of those who suffer.

²⁵ Chopp, Praxis of Suffering, 3.

²⁶ Chopp, Praxis of Suffering, 36.

²⁷ Chopp, Praxis of Suffering, 37.

²⁸ Chopp, Praxis of Suffering, 37.

²⁹ Chopp, Praxis of Suffering, 151.

Liberation theology stands within this rupture of suffering and does the traditional work of theology - it speaks of God. And in this question of suffering and this speaking of God, a new paradigm of theology is formed. For liberation theology risks the wager that only by standing with those who suffer - the poor and the oppressed, the living and the dead - shall we see the reality of human existence through their eyes and experience in their suffering a God of grace, of hope, of love.³⁰

I have found liberation theology to be helpful because it identifies with those who suffer. It represents a freedom of transformation and it acclaims a god who's love frees us for justice and faith. As Chopp says, "Liberation theology's journey is, however, radically its own: a journey with the despised and dispossessed of history; a journey dependent upon a wager of fate seeking understanding and the identification of suffering and hope with a God who creates, redeems, and liberates all of creation."³¹ Along with all of the obvious categories which liberation theology addresses, is also that of those who suffer from genetic disease. The patient is part of a population which suffers. Jesus ministered to, and in some cases, healed those who suffer. It is with this element of hope for those who suffer that I believe persons with genetic illness may identify and find meaning for their own faith expression.

In her essay titled, "Liberating Ministry," Rebecca Chopp discusses that which is involved in a theology of ministry from the standpoint of liberation ethics. She believes that liberation theology offers a challenge to modern Euro-Anglo Christianity, its churches and ministers. She raises the question as to whether churches can become centers of emancipatory transformation in our culture.³² Chopp

³⁰ Chopp, Praxis of Suffering, 151.

³¹ Chopp, Praxis of Suffering, 153.

³² Rebecca S. Chopp, "Liberating Ministry," in Clergy Ethics in a Changing Society, eds. James P. Wind et al. (Louisville: Westminster/John Knox Press, 1991),

believes that "the most striking implication for ministry and liberation theology is to work not primarily for individual needs and bureaucratic organization but for transforming the church into a community of emancipation."³³

In short, liberation theology calls for new ways and visions of being human in the church. It calls for the church to become a community of emancipatory transformation. It calls for a re-examination of the way the church currently does everything. Preaching, teaching, and the use of scripture must be adjusted to the needs of those who are truly downtrodden, whatever their plight.

Process Theology.

When one looks at process thought, on the other hand, as a way of undergirding pastoral care efforts in the light of the tragedies which befall those with genetic illnesses, one must confront again the nature of God. In process thought God is love and God is process. Process means change. God both continues and God continues to change. One might say that in the beginning was God and chaos. Out of chaos came process. Creation is continuing out of chaos. God is love, but God is not all-powerful. Evil is the chaos which has not yet become creation. Evil is the chaos which is as yet unordered. Evil can also have intentionality in the human realm but is placed there by human agents. God, therefore, is limited by chaos and incompleteness.

In his volume titled Pastoral Care and Process Theology, Gordon E. Jackson addresses pastoral care and pastoral counseling in the light of the problem of evil.

³³ Chopp, "Liberating Ministry," 95.

Jackson believes that pastoral counseling has been led away from strong theological concerns about God and about evil.

Pastoral care, especially in its more limited expression as pastoral counseling, has been sidestepping the issue of evil for a long time. Even in its more traditional expressions, for example, around the terminal illness or a grief-situation, pastoral care has too often been tongue-tied or forked-tongued when confronted with evil. In either case pastoral care fails to deal with what Jung calls the shadow-side of human experience. It fails the basic human need for meaning when it does not lift up the experience of evil into the light of interpretation. It trivializes the richness of salvation when it circumvents the evil from which we are saved.³⁴

In Jackson's view, pastoral care and pastoral counseling have missed the boat where a theological understanding of evil is concerned.

Pastoral counseling, so informed, has thus been truncated by its very patterning. Its perspective on evil has been watered down vitiating its own history in theology.³⁵

Jackson goes on to say,

Pastoral care more often ignores evil, or talks around it, as though embarrassed by it or not knowing what to do with it. In this case, the fundamental problem seems to lie not so much with the problem of evil as with the problem of God vis-a-vis evil.³⁶

Jackson is very focused, from a process theology point of view, in identifying what pastoral care has not done in terms of coming to grips with the problem of evil.

Pastoral caring in its more customary practice must come to grips not only with evil and the variegated roles it plays in life's crisis as well as normal living; it must also look again at the final Referent against which sin postures itself. And pastoral counseling, to be true to its theological ancestry, must

³⁴ Gordon E. Jackson, Pastoral Care and Process Theology (Lanham, Md.: University Press of America, 1981), 143.

³⁵ Jackson, 144.

³⁶ Jackson, 145.

develop a language about evil that points to a reality beyond the merely humanistic, one that draws the differentiation between mental disorder and human evil. The history of pastoral care, including real guilt, sin confession, penance, absolution, requires that differentiation even though significant relations between the two exist.³⁷

David Griffin is a process theologian who has struggled and written for many years concerning the problem of theodicies and evil. His point of view is useful in seeing how process theology relates to traditional theodicies:

The strategy of the traditional theodicies goes to say that God is responsible for evil but not indictable for it. But it does this without knowing the reality of genuine evil.

The general thesis of the process theodicy which follows is that the possibility of genuine evil is rooted in the metaphysical (i.e., necessary) characteristics of the world. In Whitehead's words: "The categories governing the determination of things or the reasons why there should be evil" (PR 341).³⁸

Griffin believes that in the process solution to the problem of evil, God's power is persuasive, not controlling. "God does not refrain from controlling the creatures simply because it is better for God to use persuasion, but because it is necessarily the case that God cannot completely control the creatures."³⁹

Process thought is quick to point out how the free choice of human beings, created in the image of God, contribute to the presence of evil in the natural order.

Although not totally responsible for any evil event, of course, God is responsible for all the suffering in the world of an importance sense. If God had ceased stimulating novelty prior to the advent of life, there would be no pain in the world. If God had rested content with the state of creation prior to

³⁷ Jackson, 147.

³⁸ David Ray Griffin, God, Power, and Evil: A Process Theodicy (Philadelphia: Westminster Press, 1976), 276.

³⁹ Griffin, God, Power and Evil, 276.

the emergence of animals with central nervous systems, the intensity of pain in the creation would have been low. Or if God had even ceased stimulating the development of mentality before the rise of rational creatures, the planet would have been spared its more intense horrors. Human beings have been the causes and the victims of the most horrible forms of evil experienced on our planet; and it is our species which threatens to bring all the life of the planet to a premature end.⁴⁰

Having written volumes on the subject of theodicy and evil, David Griffin offers much in the formulation of meaningful framework for discussion and definition which might be utilized by pastoral care givers. In a subsequent volume titled Evil Revisited, Griffin again addresses the problem of evil as far as process thought is concerned.

One of the hard-core commonsense notions, I claim, is the reality of genuine evil, by which I mean evil that would retain its evilness when viewed from an all-inclusive perspective. To believe in genuine evil is to believe that some things happen that, all things considered, should not have happened: The world would have been better off if some alternative possibility had happened instead. If this belief is a hard-core commonsense idea, being presupposed in practice by all persons, including those who verbally deny it, then no theodicy that denies the reality of genuine evil can be adequate to the facts of experience.⁴¹

To attempt to elucidate all of the nuances of the very detailed discussion of theodicy and the problem of evil, even from the point of view of process thought, goes far beyond the scope of this present work. Gordon Jackson has summarized the situation well for us when he says,

To believe in God means to trust this trustworthy divine element in the process. God is in tremendous struggle for any success within our

⁴⁰ Griffin, God, Power and Evil, 308.

⁴¹ David Ray Griffin, Evil Revisited: Responses and Reconsiderations (Albany: State University of New York Press, 1991), 3.

environment saturated with so much opposition and so much destructive intent. The risk of God is with our capacity not to conform to the divine purpose. Yet God as saviour is intent on making of each a fresh creation, by empathetically receiving from the world, purifying what is received, and re-constituting the world with a new vision as fresh as the next puff of experience can stand. This is the Working with which the pastor can identify in his or her caring effort to come to grips with evil in its several forms.⁴²

Most importantly, some meaningful understanding of the nature or image of God as it relates to the problem of evil is helpful if we are to forge ahead to a meaningful understanding of human life in terms of genetic and bioethical issues. J. Robert Nelson's comments are helpful at this point.

One common understanding of the image of God, as we have seen, is just that the human distinctiveness, derived from our creation in God's image, is our ability to reason to choose between good and evil, to have knowledge about ourselves, to communicate with others, and to be aware of destiny. Closely related is the belief that the image of God is that quality of life that constitutes the human dignity which all scientists, regardless of belief, should respect. Catholic theology holds that this dignity bestowed by creation in God's image is natural law and thus the basis for ethical reasoning about human life. Knowledge of it is accessible to all persons through reason and is not derived from a particular divine revelation.⁴³

The question of suffering and the relation of suffering to the creator will, no doubt, continue endlessly. I am reminded that the prime symbol of the Christian faith is the cross. The cross represents divine suffering in the person of Jesus Christ on behalf of humanity. Even Jesus questioned the effectiveness of God's love: At three o'clock Jesus cried with a loud voice, "Eloy, Eloy, lema sabachthani?" which means,

⁴² Jackson, 165-66.

⁴³ J. Robert Nelson, Human Life: A Biblical Perspective for Bioethics (Philadelphia: Fortress Press, 1984), 157.

"My God, my God, why have you forsaken me?"⁴⁴ We might ask, what is the consummate suffering of God? The answer might be, "God's suffering is wrapped up in my suffering." There is no rational escape from evil. We "suffer" loss. Evil is the experience of loss without the experience of future. Our hope, therefore is the future God which becomes effective love. Typically, we look for the experience of God in the church. Whatever healing, then, the church provides must also provide an opening to God.

Pastoral care typically avoids or ignores the problem of evil. Too often it enforces the notion that suffering is somehow God's will. Liberation theology and process theology offer hope to the sufferer in the affirmation that God suffers with those who suffer. The hope of those who suffer is the sustaining love of God.

⁴⁴ Mark: 15:34, NRSV

CHAPTER 3

Identification of Pastoral Care Needs

Leukodystrophies are the specific group at which the focus of this project is addressed. There are, however, many other debilitating genetic diseases which can lead to crisis and distress in much the same way as the leukodystrophies.

A New Frontier

We are at the dawn of an entirely new chapter in medicine and health care in this country. The proposed new National Health Care system is only part of what is happening. Concurrent with the new proposed federal legislation, the human genome project is quietly moving down the track full-speed ahead. Upon completion of this particular broad based scientific project, every gene on every chromosome in the human body will be identified and linkages and predispositions of certain diseases will be established. It will be possible to identify the probable health of every human being by identifying each individual's DNA coding. This will bring to fruition the largest accomplishment ever in the entire field of scientific medicine as knowledge about human genetics will be propelled to the forefront of medicine, ethics, and theological understanding.

I have been privileged to have shared in a new cutting edge of pastoral inquiry relating human genetics and pastoral care issues. I am grateful to the Program for Pastoral Care Education in Genetics at Georgetown University Medical School in Washington, D.C. and the Institute for the Ministry to the Sick at Johns Hopkins University Medical School in Baltimore, Maryland. I currently serve on the National

Advisory Committee for Pastoral Care Education in Genetics based at Georgetown University Medical Center, in Washington, D.C.. I am also a member of the Pacific Southwest Regional Genetics Network Consumer Committee. With my wife, Colleen, I serve as Vice President of the United Leukodystrophy Foundation based in Sycamore, Illinois.

One does not have to face a major personal tragedy with human genetics to be aware that genetics issues are becoming more and more common. There are genetic issues in every congregation. In their document titled, "The Clergy and the Genetics Patient," Frank Seydel and David Parker point out that

clergy of all faiths, who have been ordained to be spiritual counselors, can be of inestimable help to the members of their congregations who are struggling with genetic concerns. They can interpret the shared faith in ways that can provide meaning in the midst of crisis or stress. They can provide ethical and moral guidance for difficult decisions. And, they can enlist the support of the congregation in comforting the grieved and in assisting the family to cope with its problems.¹

Seydel and Parker have prepared their document to bring members of the clergy knowledge about what genetic centers and genetic counselors do and ways that clergy can complement the hospital staff in assisting persons and families who experience genetic loss or genetic concerns. We need to realize that genetic problems are quite common. The following current data is generally accepted by the medical community.

Genetic disease is the fourth largest cause of death, after heart attack, strokes and cancer. Approximately 50 percent of miscarriages are caused by chromosome abnormalities. One-third of all pregnancies end in very early

¹ Seydel and Parker, 1.

loss, miscarriage or still birth. Genetic defects are present in 6 percent of all live births, 3 percent being a serious threat to life. One-third of infant mortality is due to genetic factors. One percent of all persons have mental retardation due to genetic reasons. One-third, or more, of children admitted to hospitals are there for genetic reasons. One in ten American couples is infertile. Genetic factors are a common cause of infertility. There are over 4,000 known genetic disorders and birth defects; and new ones are detected every year. Each of us carries at least four to eight recessive genes for genetic disorders.²

As Seydel and Parker have pointed out:

Some genetic disorders are relatively common, such as Downs Syndrome or Spinabifida, which occur once in approximately 800 births. Others are so rare that only a few persons in the entire United States have been identified. Fortunately, many deleterious genes are not usually expressed. When they are, the result can be disfigurement (e.g., neurofibromatosis), serious impairment, (e.g., sickle cell anemia), chronic disability, (e.g., cystic fibrosis), physical degeneration (e.g., muscular dystrophy), mental degeneration, (e.g., Huntington's disease), or early death (e.g., Tay-Sachs disease).³

Metachromatic leukodystrophy, which has stricken our daughter, Kristy, has an incidence of 1 in 40,000 live births. Statistically, this means that the largest non-governmental hospital on the West Coast, Memorial Hospital Medical Center in Long Beach, California, might see one live birth in ten years. This is, indeed, a rare occurrence.

Rare genetic occurrences drastically and tragically change lives. Over the last ten years as Vice-President of United Leukodystrophy Foundation, I have identified three things which often occur in families which have persons stricken by one of the leukodystrophy diseases: (1) the family goes financially bankrupt; (2) the parents

² Seydel and Parker, 2.

³ Seydel and Parker, 2.

separate and divorce; and (3) the genetically affected patient dies. These three things may happen in any order and, in fact, do occur in many families who experience the tragic circumstances of debilitating genetic diseases.

As has been stated above, the focus of this project is limited to families and persons affected with the group of diseases known as leukodystrophy, as an example of genetically based problems which often precipitate the crisis concerns that are addressed in this project.

About Leukodystrophy

The term Leukodystrophy refers to a group of diseases which effect the brain and spinal cord. The word, leukodystrophy, derives from the Greek words, "leuko" meaning white in referring to the white matter of the nervous system and "dystrophy" meaning imperfect growth or development.

White matter actually appears white to the naked eye because it contains a complex chemical substance called myelin. Myelin contains a variety of fatty substances which appear shiny and white. The function of myelin is to insulate the axon, a tiny strand of nerve fiber, through which the nerve impulses are conducted much as insulation around electric wire protects the wire as it conducts electricity.

When the term dystrophy is used in medicine, it is meant to imply a condition which is genetically determined and which is progressive; that is, the condition tends to get worse as the patient gets older.

The leukodystrophies almost always effect infants or young children usually beginning before the age of twenty years. These diseases impair the patient's ability

to move and think, to see, hear and feel. Once the diseases manifest themselves, they become worse over time. Sometimes this worsening is rapid and sometimes it may extend over a period of several years. The patient effected with the leukodystrophy dies, usually within one to ten years after diagnosis.

Early in my graduate theological training, I spent a summer quarter in clinical pastoral education in a general hospital setting. I was subsequently hired to be on the pastoral care staff of that hospital (part-time) through the balance of my seminary years and early into my parish ministry. Not once did I ever hear the word genetics mentioned. This is still too often the case, both in the academic and pastoral training of clergy. I find this situation quite troubling in the light of the statistical facts concerning genetically based diseases.

In their article titled "The Leukodystrophies," Brown, Stowens, Harris and Moser point out:

The severity of medical problems compounded by the necessity of coping with a fatal illness poses a serious threat to family functioning. One may envisage three major areas about which family crisis may develop: (1) establishment of the diagnosis and discussion of its implications; (2) living with the child at home as the neurological deterioration progresses; and (3) future family planning. In many instances, the screening of siblings and what to tell them about their disease, is also an issue. How the families cope with these events depends on the support that family members can offer one another and on the ability of each to adapt to loss, both potential and actual.⁴

If family support systems are inadequate, additional help in the form of support groups and organizations may be indicated. Individuals in crisis normally show signs of distress that illicit care from others, be they relatives, friends, neighbors, or professionals. If this does not occur spontaneously, it

⁴ Frank Brown, III et al., "The Leukodystrophies" in Current Therapy and Neurological Disease, 1985-1986 (New York: B.C. Decker, 1985), 316.

may be appropriate for the professionals involved to arrange active support. Bringing in other parents who have faced similar crisis can be particularly helpful. Support group members are usually non-professional, but professional advice is available as needed. The United Leukodystrophy Foundation, Inc. (2304 Highland Drive, Sycamore, Illinois 60178; (815) 895-3211) was incorporated in 1982 to provide support for families; it generates a quarterly newsletter and monthly mailings to discuss current research, patient management, and the personal experiences of families coping with leukodystrophies. Members meet annually and maintain regular telephone contact. Through helping one another, families enhance their ability to cope with their own situation.⁵

Religious Issues and Responses

There are also certain religious issues raised by genetic problems. Seydel and Parker point out that,

Numerous religious issues are raised as families attempt to make decisions about family or cope with genetic loss or potential loss. These religious concerns cover the spectrum of theology, ethics, and pastoral care. Pastoral guidance can be most beneficial in helping families to cope with these myriad, and sometimes conflicting issues.⁶

Included among theological issues in genetics are questions such as, what does it mean to be human? What is the nature and role of the family? Should one strive for genetic perfection? Why do bad genetic mutations happen? What is the nature and means of God's grace for persons who make "poor" genetic decisions? Is recombinant DNA technology (genetic engineering) playing God?

There are also ethical issues which arise. These might include, what forms of contraception are acceptable? Under what conditions is assisted reproduction acceptable? When is abortion acceptable? How should critically ill newborns be

⁵ Brown et al., 316.

⁶ Seydel and Parker, 4.

managed? Should screening for genetic disease be mandated? How does one compare the risks and benefits of prenatal testing? How does one measure quality of life? Who pays the cost for expensive procedures?

Pastoral care issues must also be considered. Who counsels, clergy and/or lay persons? What role should support groups play? Should counseling be directive or non-directive? What is the obligation of the pastor to relatives at risk or to the unborn child? How can the pastor assist reconciliation between the church and families, when those families make decisions in opposition to church doctrine? How can a local congregation be constructively involved?⁷

First of all, any response must begin with a recognition of much of the above, that is human genetic issues are a major life concern for many people. Many genetically diseased persons progress through the tragic course of their illness and die quietly at home, out of public view and the notoriety which a hospital setting may often bring. Because genetic illnesses are often slow and long term, it is easy for genetic patients to become the forgotten ones, both in society as a whole as well as the religious community. These are the ones about which the religious community and the pastoral care of the church, also, may easily forget.

⁷ Seydel and Parker, 4.

CHAPTER 4

Review of Research Questionnaire/Responses by Leukodystrophy Families

A special pastoral care research inventory instrument was designed in the summer of 1991 in order to elicit responses from leukodystrophy families concerning the nature and extent of pastoral care that respective families have received. The ten questions on this brief inventory were designed to determine:

1. religious preference and orientation, if any;
2. type of Leukodystrophy in the respondent family;
3. whether or not the respondent was active in the practice of their preferred religious faith;
4. the extent to which the respondent's minister, priest, rabbi or spiritual leader was aware of their family situation with regard to Leukodystrophy;
5. whether or not the respondent had sought to inform their spiritual leader concerning the particular pastoral care needs of their affected Leukodystrophy family;
6. the extent to which adequate and on-going pastoral care sensitive to the respective situation is being supplied;
7. whether or not the respondent has received any type of pastoral care from a hospital or institution based chaplain;
8. and if institutionally based pastoral care was rendered, the extent to which it was adequate or sensitive to the particular needs of their family;
9. what specific needs are expressed in terms of pastoral care which have not been received; and

10. any comments on any aspect of pastoral care in their particular situation which might be useful to someone else in the future.

The research inventory was offered to a field of nearly 200 participants in an annual week long scientific meeting and family support workshop setting at Northern Illinois University in Decalb during July of 1991. Only 28 completed responses were returned. Those who submitted completed inventories represented a broad base of variances among the Leukodystrophy diseases. Most were somewhat active to very active in the practice of their religious faith. Among those who were active in the practice of their faith, it was felt that their spiritual leaders were at least somewhat aware of the needs of the Leukodystrophy family. Most had informed their spiritual practitioners concerning their family needs, at least to some extent. However, less than half felt that their on-going pastoral care was adequate and appropriately sensitive to their particular situation. Many felt that pastoral care to them was not at all adequate and a few indicated that it was sufficient only to some limited extent. Most respondents reported that they had never received pastoral care from a hospital or institution based chaplain. Among those who had received chaplaincy care, the response that it was overwhelmingly useful and meaningful for them at the time.

Most families who responded indicated that they still have significant needs for support, prayer and an active interest on the part of their spiritual leader regarding their family situation. Many indicated the need for congregationally based support groups which might include such topics as grief therapy, healing ministry, discussion, general support of presence and a recognition that persons are working with illnesses

that do not go away. There was a strong need expressed for pastors and spiritual leaders to get to know the Leukodystrophy families well. Another strong recommendation was to set up groups of caring volunteers within the life of the congregation to make scheduled visits to affected families.

Subsequent to the tabulation of the research questionnaire, six families were personally interviewed by telephone concerning some additional input that was omitted in the original questionnaire. The question of how respondents dealt with inner feelings of abandonment by God, if any, was raised. In every case in this random sampling of six respondents, it was indicated that somewhere early in the process of discovering the genetic problem, there were feelings of anger, hostility, abandonment, and suffering. All indicated that there were times when, in fact, God seemed very far from them in their suffering.

Also, in every instance in this random sample of six respondents, each situation had, sooner or later, come to a better place of understanding and acceptance of their situation. Those who had reached out to the church or to their pastor indicated they had received some spiritual uplift, if only that of the presence of the spiritual leader or other members of the congregation who expressed care and concern.

In the theological categories of liberation ethics and process thought, the experience of God in one's suffering, the ministry of presence, is a powerful and uplifting reminder that God is present in the world of those who suffer. God's love is shared by those who care when persons in need accept the outreach of a caring person

or congregation. This sharing of God's love on a personal level is a powerful affirmation of God's presence.

CHAPTER 5

Models of Response: Summary and Conclusions

It is clear that the emerging awareness of genetic issues as a factor in the need for pastoral care is bringing with it the awareness of the need to respond in several arenas.

Only a few seminary curriculums in graduate theological schools are beginning to offer courses which include genetic issues among disabled and handicapped concerns. Union Theological Seminary in New York City has been one of the pioneers in seeking to teach seminarians about the awareness of Americans with disabilities. This is due in large part to the work of Harold Wilke, who teaches at that institution. The School of Theology at Claremont offered a brief course in the summer term of 1991 and is planning a second offering of a similar course during the winter term in January, 1994. It is interesting to note that here the guest faculty member will be none other than Wilke. Some workshop and course work has also been offered at Wesley Theological Seminary in Washington, D.C.

Continuing professional education experiences for ordained clergy in the field of genetics and pastoral care have been sparse, indeed. There have been two or three institutions across the country that are pioneers. The most comprehensive program available to date has been a week long intensive course at Georgetown University Medical School in Washington, D.C. There, a comprehensive training program for pastoral care education in genetics has been developed by Frank D. Seydel, Ph.D., a United Methodist minister from the Iowa Conference who teaches in the division of

genetics in the department of OB/GYN at the medical school. Georgetown has since become the center for the National Advisory Committee on Pastoral Care Issues and Genetics. This is a board on which I am currently an active member. The only other on-going academic continuing professional education program in genetics and pastoral care has been developed at the University of Wisconsin in Madison. The model utilized there has been a more brief (2-3 day) workshop format. There have also been some attempts at cross training by the University of Washington relating to the human genome project. In this instance, physicians and clergy were given intensive training in the other's respective field and then spent time together dealing with bioethical issues.

As the mapping of the human genome proceeds to fruition, many issues will surface which will need the attentive care of clergy and pastoral counselors everywhere. It is, therefore, incumbent upon the academic community to gear in to current scientific endeavor and prepare clergy to better be able to be of assistance to families with a wide variety of genetic needs.

Very little has been written in terms of local church curriculum which might be used for study where issues in genetics and pastoral care are concerned. Harold Wilke's healing community has offered some materials which are useful in the general field of disability. The Presbyterian Publishing House has also made available an

offering titled, "Rediscovering God's Image: Including People With Disabilities" in the 1992 foundational current issues curriculum.¹

The Human Genome Project

In 1990, a massive effort was launched conjointly by the National Institutes of Health and the Department of Energy. This has come to be known as the U.S. Human Genome Project. This undertaking is part of an international effort to develop genetic and physical maps in order to determine the DNA sequence of the human genome and the genomes of several model organisms. Over two hundred million dollars annually has been planned each year for the first five years in order to fund this task. The initiative itself, is scheduled to run for fifteen years in order to fully complete the defined effort of mapping and the sequencing of the "whole genome." Much of the work will, in fact, be completed by the end of 1995.

Every cell in the human body has about 6 feet of DNA material which is an individual and specific code for the entire organism. Eventually, it will be possible for each human being to have access to and utilize the information from their own respective DNA code. Obviously, this will bring about broad public impact as the genome project progresses. New public policies will be needed to anticipate the potential consequences of wide spread uses of genetic tests. Predispositions to certain ailments, including cancers as well as known disease-related traits, will be able to

¹Frank T. Hainer, et al., Foundational Current Issues: Curriculum Units I and II (Louisville: Presbyterian Publishing House, 1992).

be determined. It is expected that the DNA sequencing of the human genome will reveal a wealth of biological information that could not be obtained in other ways.

The genome project has already had an impact on biological research. In the last few years the genes for metachromatic leukodystrophy and adreno leukodystrophy, two of the main diseases in the leukodystrophy group, have been identified and cloned. Genes that also indicate a pre-disposition to other more common diseases such as breast cancer, hypertension, diabetes, colon cancer and Alzheimer's disease have also been identified in their specific chromosome regions.

The technology and data produced by the genome project will forever change the way medicine and medical practice is conducted.

Within the organizational structure for the National Center for Human Genome Research is a division of extramural research which has a branch for ethical, legal, and social implications. This ELSI branch explores ways to ensure responsible use of the genetic information that will become available as a result of genome research. It is important, that concurrent with the pure scientific research, there is also supportive research to anticipate and resolve the ethical, legal and social issues arising from human genome research. A responsible use of information dictates that these concerns be explored. In such an arena, the role of clergy and bioethics cannot be over stated.

It should be incumbent upon all clergy, churches and religious institutions to become familiar with the human genome project and its impact upon our society and how the medical information provided will be utilized in the human arena.

According to the U.S. Department of Human Health and Services,

Most inherited diseases are rare, but taken together, more than 3,000 disorders known to result from single altered genes rob millions of healthy and productive lives. Today, little can be done to treat, let alone cure, most of these diseases. The National Institutes of Health, one of the major players of the human genome project, invests in the search for genes because having a gene in hand allows scientists to study its structure and characterize the molecular alterations, or mutations, that result in disease... The goal of the human genome project is to provide scientists with powerful new tools to help them clear the research hurdles that now keep them from understanding the molecular essence of other tragic and devastating illnesses, such as schizophrenia, alcoholism, Alzheimer's disease, and manic depression.²

The National Institutes of Health has pointed out that,

The six-foot thread of DNA inside each human cell might be thought of as the thread unifying all of humankind. Because information about the human genome will be applicable to the entire human race, other U.S. agencies and indeed programs in other countries will also fund and carry out the goals of the genome project.³

After more than ten years of struggling with a debilitating and tragic genetic disease with our daughter, Kristy, I have discovered that it is possible for clergy to learn the scientific language of genetics and to begin to be aware of the tremendous consequences of the human genome project in the human arena. This is, indeed, a new frontier of inquiry. It ought to include clergy and religious institutions because these are the traditional sources of support and moral grounding where decisions are made.

² U.S. Department of Health and Human Services, Public Health Service, National Institutes of Health, The Human Genome Project: New Tools for Tomorrow's Health Research (Bethesda, Md.: NIH, 1992), 5.

³ U.S. Department of Health and Human Services, 18.

Education and counseling are vital components of the genetic testing process.

While most clergy may not learn the scientific language of genetics, they do need to know where and how genetic testing and counseling take place. Who does it, when it is done, and, how decisions about genetic information are made, are critical concerns for all of us. The guidance of families in using genetic information in a manner consistent with their own values and beliefs is an enormous task that faces all care givers, especially those involved in pastoral care.

Already, serious questions are being raised as to the adequacy of the currently available laws and regulations to address the potential of using genetic information in unfair and discriminatory ways. Every pastor and religious leader needs to be informed and needs to have resources immediately available to deal with genetic concerns.

Seminary Curriculum

As is discussed in Chapter 3, this author believes fervently that graduate theological education needs to rise to the occasion of both awareness and critical review of genetic issues, including the human genome project. For too long and in too many ways, seminary curriculum is often "the tail wagging the dog," when it comes to the real crucial issues of human life in our society. Certainly, genetics issues are fast becoming an arena that must not be avoided.

While it has been true for many years that courses in ethics and bioethics, as well as pastoral care and counseling, have been offered in most accredited seminaries, the word "genetics" is rarely heard or spoken. As I have already noted, academic course

work is sparse, indeed, where the subject is concerned. With genetic issues present in every congregation, pastors need new tools of information, awareness, and counseling, which will enable families and children with genetic issues to receive more appropriate pastoral care.

Courses and practicums in clinical pastoral education need to have a component which focuses on human genetics and bioethical issues. Inroads into traditional graduate theological education models have been slow. Even attendance at those opportunities which are offered remains relatively sparse.

For example, in February 1992, two other colleagues and I made a major workshop presentation at the College of Chaplains meeting in Anaheim, California. This was a national meeting of the protestant health care community. Less than twelve people attended our ninety minute presentation which had been well publicized in advance. An annotated bibliography was prepared by Frank Seydel, Cory Smith, and me for this event. A copy of that material is included as Appendix C of this current work.

Curriculum for the Local Church Congregation

There is little to nothing that I have been able to find concerning Christian education curriculum focusing on genetic issues which has been written for use in local church congregations. There has been some work done, however, in the area of persons with disabilities as a general category. Most notable here are offerings by the Healing Community -- The Caring Congregation, a journal dedicated to help congregations become accessible in attitudes, architecture and communication to the

disabled, frail elderly and other vulnerable persons. This is the organization so ably founded and directed by Harold Wilke. From this organization a brief study guide for congregations and religious leaders concerned with persons with disabilities is available.

The Presbyterian Publishing House in its foundational current issues curriculum has also put forward a study unit titled, "Rediscovering God's Image: Including People with Disabilities." This material was published in 1992 and discusses historical issues, the image of God and disability, understanding miracles, science of a new faith, and the issues of accessibility in the life of a local church congregation.

An appropriate sequel to either of the above offered possibilities, or as a unit of independent study unto itself, might be a study constructed with the concerns that this author describes in this project. Such a study might include a review of both liberation theology and process thought where there is a clear theological grounding of hope for those who suffer and an affirmation that God also suffers with those who suffer. This, after all, is the mission of the church - to proclaim the sustaining love of God amidst the suffering of all of humanity.

If the church is to engage the real world, it must include the world of genetic disease and suffering. This is a world of more than twelve million Americans. It is a world where genetic issues are present in every local church congregation. Both education, awareness, and acceptance of genetic issues as a major concern of our time will be among the best first steps that the church can take as it seeks to extend pastoral care to those afflicted with genetic concerns. Even in such a contemporary

issue as homosexuality, the church fails if it does not recognize the genetic implications that are present and, therefore, must be acknowledged in any discussion of homosexual issues.

Program Models for the Local Church Congregation

Local church congregations, the established Christian fellowship communities, have the potential for reaching out in specific and tangible ways to the needs of those families affected with genetic disorders. Many churches have both the physical plants that may be utilized to house specific programs, as well as professional staff and lay volunteers who may be available to provide both primary leadership and assistance with certain program needs. The educational agenda is an important task, but also of paramount importance is the actual one-to-one caring which is the real hallmark of the Christian community.

Parents Day Out

As the research data in Chapter 4 indicates, many families have needs which the local church congregation can help meet. One of those needs is for respite care. Many community and government agencies are set up to provide certain kinds of respite care on a long-term basis. Certain sheltered day care centers and other programs such as public school programs for the handicapped may be utilized on a daily basis, Monday through Friday during normal business hours.

This writer envisions a half day program on Saturdays where parents may take affected children for a meaningful fellowship activity at church during which time the parents would be free for brief personal business or a few hours of respite relaxation.

Most State and local governments do not interfere with church programs such as this when they are brief in nature. For example, in the State of California, a church may operate a half day program as part of its ministry without being subject to the myriad of State and social service agency requirements when the program is limited to four hours on one day a week, in addition to the church's regular Sunday schedule of activities.

A program on Saturdays from 10:00 a.m. until 2:00 p.m. which provides fellowship, and Christian nurture for affected children with genetic disorders at church could be a meaningful offering to the community. A lunch might be provided for a nominal fee. Workers in the program might include those who are licensed vocational nurses, registered nurses, trained social workers, and a host of lay volunteers who could provide a loving environment and half day program while parents have discretionary free time for whatever purposes are needed most by them. The program for children with genetic disorders in this half day model might include some form of Bible study and/or religious instruction, a fellowship time including games and recreation, craft time, meal time, and rest time for those who need it.

A church fellowship hall with an adjoining kitchen and standard equipment would be an ideal setting. Certain special equipment might be acquired which could include cots for those who need to have naps and other durable equipment as might be required by certain individuals in the constituent group. Most patients will have their own wheel chairs and other durable equipment appliances which are portable and can easily be transported to the site of the parents day out program.

The space being utilized for the program should be climate controlled, have good wheel chair and handicap access, with restrooms that are also handicap equipped.

Persons volunteering to assist with this type of program need to be aware and be informed as to the types of genetic disorders that may be present in the program and what medical and social skills are required of the volunteer care givers. Patients with severe afflictions may very well be accompanied by their own private duty nurses or attendants. Lay volunteer care givers may derive significant satisfaction from this type of ministry.

A parents day out program of the type being described here might be a single ministry of a given local church to its own constituency if it is a large church, or it might become a community based or regional ministry involving the participation and support of a wide number of a wide range of churches in a given geographical area or denominational structure. Some churches already focus on specific ministries either to the blind or deaf, for example. Not only would this type of ministry serve a population who desperately need this type of program, it could also be an important outreach to the church's own growth in the community.

Genetic Support Group

A second local church program which might be initiated to minister to families with genetic concerns would be a support and discussion group. The research results in Chapter 4 clearly indicate a need for families with genetic disorders to get together and communicate both for information and social support. In all practicality, this type of group is no different from any other interest or support group sponsored by a

local church congregation. It is the subject and the clientele that are perhaps new and unique for the church.

To begin, one might offer a guest lecturer and discussion on an identified need of a number of families with genetic disorders. Topics might cover such concerns as health insurance, special education, private duty nursing, augmentative communication, and traveling with a patient with special needs. A guest speaker might be a local physician, a special education expert, or a physical therapist specializing in the needs of handicapped children.

An initial or one time event such as this could be widely publicized and attendance solicited across the community or through a wide number of churches in a given denomination or on an ecumenical basis. From that initial offering, one might determine the need for an ongoing discussion or support group in the community. A mental health professional or pastor who would volunteer to shepherd such a ministry would be an ideal leader to help meet the needs of this special interest group of persons. A schedule of group discussions from time to time might include a variety of topics from basic Bible study to specific health interest concerns.

Most important here would be the development of a support network among affected families where love and understanding can be shared within the context of the Christian community.

The local church has endless possibilities for expanding its ministry if it is willing to address those persons in need within its respective constituency.

In his monograph titled "From Brokenness to Community", Jean Vanier talks about the meaning of Christian community. He says this:

There is only the possibility of real growth in a community if people are deeply respected in their personal development. We continually need to have before us the challenge of our mission. We are not in a community just to protect ourselves. We are not even there just to protect our own little spiritual lives. We're there for the church, for people in pain. We have a message to give, and we have a message to receive. We have a mission, and if we are not a people of mission, then the community is in danger of closing up, and of dying.⁴

More That Can Be Done

As science brings to bear its vast wealth of information on biological issues to medicine, so must the church also step forward into a new and challenging frontier which offers grace and healing to those who are troubled and afflicted. For the church to ignore the arena of genetics is to deny the reality of human life which surrounds it.

If the church is to take genetic issues seriously, I envision a whole new range of ministries extending to persons throughout the given sphere of influence of every local church congregation. Support groups for information, sharing, advocacy, and fellowship could abound. The churches need information about various medical issue support groups and societies that function in specific arenas of genetic concern. Persons with genetic problems need to feel that they are welcome, and that they are whole and complete in God's sight, and in the fellowship of the church.

⁴ Jean Vanier, From Brokenness to Community (Mahwah, N.J.: Paulist Press, 1992) 48.

The church could, once again, become a strong base of advocacy for human rights where genetic issues are concerned. The church can help in formulating a myriad of new bioethical guidelines and approaches which all need to be developed as the human genome project proceeds on its course.

While much of that being discussed here is perhaps, a "new twist" for the social gospel, these are the issues to be confronted in our time if the church is to remain relevant in the society in which we live.

In the research sample of leukodystrophy families described in Chapter 4, it is clear that the church is sorely lacking in almost every area of pastoral care and concern where genetics issues may be addressed. The challenge is to open the door of the church, which is a closed society, to the whole world of creation where the love of God needs to be shared and transmitted to people in need.

APPENDIX A

Pastoral Care Research Inventory

Thank you for taking the time to respond to this brief research questionnaire.

As a leukodystrophy family, you may have experienced that the religious community and its professional clergy have little awareness of your particular kind of situation, and perhaps little or no training in how to assist families in such circumstances. ULF Vice President, the Rev. William Kintner, is currently engaged in a research project at the School of Theology in Claremont, California. It is the intention of his project to design better curriculum for both the training of clergy and for use in the local congregation which will more usefully serve families and persons with handicapping conditions such as the leukodystrophies. Mr. Kintner is a United Methodist minister and a licensed psychotherapist. He currently serves as the senior pastor in charge of the Valencia United Methodist Church in Placentia, California.

- 1) Please indicate your religious preference, if any.
 - A) Jewish
 - B) Protestant
 - C) Roman Catholic
 - D) Other (please indicate) _____
 - E) None

- 2) Please indicate type of leukodystrophy in your family. _____

- 3) Are you active in the practice of your religious faith?
 - A) Very active
 - B) Moderately active
 - C) Somewhat active
 - D) Little, if at all
 - E) Other (please describe) _____

- 4) Is your minister, priest, rabbi, or spiritual leader aware of your family situation with regard to leukodystrophy?
 - A) Yes
 - B) No
 - C) Somewhat
 Comments: _____

- 5) Have you informed your minister, priest, rabbi, or spiritual leader about leukodystrophy and the particular pastoral care needs of your family?
 - A) Yes
 - B) No
 - C) To some extent
 Comments: _____

6) Do you, or does your family receive adequate and ongoing pastoral care that is sensitive to your situation from your minister, priest, rabbi, or spiritual leader?

A) Yes

B) No

C) Sometimes

Comments: _____

7) Have you ever received pastoral care from a hospital or institution based chaplain?

A) Yes

B) No

8) If "Yes" (in #7 above), was it adequate and sensitive to your personal or family needs?

A) Yes

B) No

Comments: _____

9) What do you need (or did you need) in terms of pastoral care from your minister, priest, rabbi, or spiritual leader which you have not yet received?

Comments: _____

10) Please comment on any aspect of pastoral care in your particular situation which might be useful to someone else in the future. (Please attach a separate sheet if more space is needed.)

Thank you very much for your response to this research questionnaire. Please turn in this sheet before you leave the ULF Conference.

Optional:

Name _____

Address _____

_____ Zip _____

Telephone Area Code () No. _____

APPENDIX B

Pastoral Care Research Inventory Responses

Total Number of Responses - 28

1. Religious preference -

Jewish	0
Protestant	18
Roman Catholic	8
Other	0
None	2

2. Type of Leukodystrophy

Alexanders	2
ALD	8
AMN	4
Krabbes	1
MLD	8
Sudanophilic	1
Zellwegers	3
Undiagnosed	1

3. Practice of religious faith

Very active	11
Moderately active	6
Somewhat active	5
Little if at all	2
None	4

4. Religious leader's awareness of family situation with regard to leukodystrophy

Yes	17
No	4
Somewhat	5

5. Have you informed your religious leader about your needs?

Yes	14
No	10
Somewhat	2

6. Do you or does your family receive adequate pastoral care sensitive to your situation?

Yes	12
No	8
Sometimes	6

7. Pastoral care from hospital or institution-based chaplain

Yes	10
No	18

8. If "yes" in #7 above, was it adequate or sensitive?

Yes	8
No	1

APPENDIX C

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Coping with Genetic Loss and Disability
Frank D. Seydel, Corey B. Smith, and William L. Kirtner
For further information contact: Frank D. Seydel, M.Div., Ph.D.
Program for Pastoral Care Education in Genetics
Georgetown University Medical Center
Washington, D.C. 20007

Antovnowsky, A. Health, Stress and Coping. San Francisco: Jossey-Bass Publishers, 1985.

Provides detached examination of mechanism whereby families seek to reduce stress and maintain esteem and wholeness in the midst of health struggles.

American Association for the Advancement of Science. The Genome, Ethics, and the Law. Issues in Genetic Testing. A Report of a Conference on the Ethical and Legal Implications of Genetic Testing. Washington, DC: American Association for the Advancement of Sciences, 1992.

An excellent overview for non-geneticists of the implications of the federally-funded Human Genome Initiative on privacy and confidentiality. In particular, concerns regarding insurability and employability are examined.

Bouma, Hessel III, et al. Christian Faith, Health and Medical Practice. Grand Rapids, MI: William B. Eerdmans, 1989.

Explores a number of medical ethical issues including genetics from an explicitly evangelical Christian point of view. Provides the theological background for the ethical inquiry.

Cobb, John B., Jr. Matters of Life and Death. Louisville: Westminster, John Knox, 1991.

Using a bioethical approach, Cobb addresses sensitive and controversial issues facing both the church and society in today's world. Four major topics are discussed, 1) animal well-being, 2) death with dignity, 3) the moral status of the fetus, and 4) sexuality outside of marriage. Cobb demonstrates how careful and consistent ethical and theological reasoning can provide a balanced and humane ethic for our time.

Colston, Lowell G. Pastoral Care with Handicapped Persons. 1978. Reprint. Ann Arbor: University of Michigan, Out-of-Print. Books on Demand, 1991.

This volume is written from the insights of long years of teaching and practice of pastoral counseling. Somewhat autobiographical in nature, there is a special depth of understanding of physical disabilities. Colston discusses in detail the values of coping creatively with handicaps and developing positive potentialities. He identifies a model of pastoring he describes as "pastoral advocacy."

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Fletcher, J.C. Coping with Genetic Disorders: A Guide for Clergy and Parents. San Francisco: Harper and Row, 1982.

Ilse, S. Empty arms. Long Lake, MN: Wintergreen Press, 1990.

Jones, Monica Loose. Home Care of the Chronically Ill or Disabled Child. New York: Harper and Row, 1985.

The majority of disabled or chronically ill children are cared for (and die) at home. A loving and caring family offers an ill or disabled child an emotional environment far more stable and healthy than that found anywhere else. In many areas of the United States (and the rest of the world) community resources in health care and professional help for chronically ill or disabled children are extremely limited or nonexistent. This is a practical volume which teaches parents about the daily care of an ill or disabled child, and how to respond to emergencies.

Lamb, J.M. Bittersweet . . . Hello, Goodbye: A Resource in Planning Farewell Rituals when a Baby Dies. Springfield, IL: Prairie Lark Press, 1988.

Minnick, Moly. A Time to Decide, a Time to Heal. East Lansing, MI: Pineapple Press, 1990.

Discusses pregnancy loss, especially for wanted pregnancies. This book is written for those who are facing or have experience with pregnancy loss. The book is especially helpful for persons dealing with the termination due to birth defects of a wanted pregnancy.

Ohsberg, H. Oliver. The Church and Persons with Handicaps. Scottsdale, PA: Herald Press, 1982.

This volume attempts to arouse the conscience of the church regarding ministry to persons with disabilities. It suggests some guidelines to those in the local church who feel the burden to begin a ministry to the disabled and their families. Ohsberg approaches the subject from a developmental basis. He attempts to give understanding to those who will be engaged in ministry to handicapped persons.

Rando, T. (Ed.). . Parental Loss of a Child. Champaign, IL: Research Press, 1986.

Seydel, Frank D., ed. Resources for Clergy in Human Genetic Problems. 2nd ed. Washington, DC: National Center for Education in Maternal and Child Health, 1988.

This is a comprehensive annotated bibliography of both books and periodical articles. The emphasis has been placed on the role of clergy in particular in dealing with concerns in human genetics. This resource helps to aid clergy in the familiarization with genetics and the need for a new ministry which has been dramatically stimulated by the rapid expansion in the diagnosis and treatment of birth defects and genetic disorders.

Volner, Martha (ed.). Health Insurance Resource Guide. White Plains, NY: March of Dimes, 1992.

Prepared by the Alliance of Genetic Support Groups, this is a practical guide for obtaining and keeping health insurance, and getting insurance companies to pay claims when a genetic disorder is diagnosed.

Wilke, Harold H. Creating the Caring Congregation: Guidelines for Ministering with the Handicapped. 4th ed. Nashville: Abingdon, 1983.

This book sets forth guidelines for the congregation attempting to respond to the needs of handicapped individuals. Special attention is given to what Scripture has to say about persons with physical disabilities and reviews how the church has traditionally responded to such people - both positively and negatively. A handicapped individual himself, born without arms, Wilke is devoted to the purpose of restoring alienated and handicapped persons to the mainstream of community life.

Organizations

Alliance of Genetic Support Groups. 35 Wisconsin Circle Suite 440, Chevy Chase, MD 20815. 301/652-5553 (MOD), 1-800-336-GENE. The mission of the Alliance is to serve as a coalition of voluntary support groups for individuals and families who have genetic disorders; it also serves to enhance communications between these persons and health care professionals.

March of Dimes Birth Defects Foundation. 1275 Mamaroneck Avenue, White Plains, NY 10605. 914/428-7100. Works toward the prevention of birth defects through the support of research and the provision of medical services and education.

National Center for Education in Maternal and Child Health (NCEMCH). 2000 15th Street North, Suite 701, Arlington, VA 22201-2617. 703/524-7802. Provides information services, educational materials, and technical assistance to organizations, agencies, and individuals with maternal and child health interests.

National Organization for Rare Disorders (NORD). P.O. Box 8923, New Fairfield, CT 06812. 800/447-6673 or 203/746-6518. The NORD is dedicated to the identification, control, and cure of rare disorders. To achieve these goals, NORD operates programs of education, service, and research.

Pregnancy and Infant Loss Centers. 1421 East Wayzata Blvd., Suite #40, Wayzata, MN 55391. 612/473-9372. A national non-profit organization offering support group information, literature, and educational outreach to professionals on miscarriage, stillbirth, and infant death.

United Leukodystrophy Foundation, Inc. 2304 Highland Drive, Sycamore, IL. 60178. 815/895-3211, 1-800-728-5483. The Foundation is a non-profit, voluntary health organization incorporated in 1982. Its purposes are: (1) To provide leukodystrophy patients and their families with information about leukodystrophy and to assist them in identifying sources of medical care, social services, and genetic counseling; (2) To establish and coordinate a communication network among affected families; (3) To increase public awareness about leukodystrophy and to act as a source of information for health care providers. (4) To promote and support research on the causes, treatment, and prevention of the leukodystrophies.

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